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Supporting Parents to Support Family Life: A Central Challenge for Family Minded Policy

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Disabled parents can experience difficulties when trying to access services to support their parenting role, and this is exacerbated wherever disability continues to be articulated as if it were impairment and associated with a need for 'care'. Disabled parents and their families experiences of services demonstrate that, for a family approach to be positively developed within social policy, individuals should be kept in sharp focus by policy makers, practitioners and researchers. Failure to do so can result in the problematisation of parents who have support requirements, itself a barrier to the development of appropriate services for parents and families.

Introduction

This article has developed from a concern that individuals within families need to be kept in sharp focus by policy makers, practitioners and researchers at a time when 'the family' has re-emerged as a core focus within social policy (Parton, 2009). This is not least so that individuals who have support requirements in their own right are not problematised or marginalised through the mis-application of risk-based lenses by those who shape, deliver and evaluate services. Morris and Featherstone (2010) identify that 'parent' and 'parenting' are terms often used within deficit-based accounts of policy and practice with families who have been identified specifically as having care or protection needs. This can have wider implications for those families who are the focus here, that is families which include a parent or parents who themselves have support requirements and who experience impairment or long-term health difficulties. If parenting roles are predominantly considered in relation to risk rather than support, many parents may find it difficult to have their own experience represented and accounted for in both policy and practice.

Support for parents living with an impairment or a long-term health difficulty and who have social care support needs may not become prioritised unless, or even where, a 'families (or children) at risk' approach is undertaken. This article reviews a developed body of literature to explore the experiences of disabled parents and their families. This provides the basis for a critical analysis of the ways in which parents have been represented within the *Think Family* policy stream which itself has been informed by a risk analysis of 'parent-based social exclusion indicators' (SETF, 2007: 62).

'Disabled parents': an inclusive definition

Within this article, the term 'disabled parents' is used to include parents who have a physical or sensory impairment, parents who identify as Deaf, parents who have a

learning difficulty/disability, parents who experience mental distress, parents with long-term chronic health conditions (including HIV and AIDS) and parents who have support requirements due to alcohol or other substance misuse. There is acknowledgement here that not all those included within this definition will identify with the term 'disability', and that some may not be defined as 'disabled people' under current legislation. It is also recognised that disability is but one of a range of structural factors influencing the experience of disabled people as parents (alongside those based on gender, economic disadvantage, ethnicity and sexuality) (Olsen and Clarke, 2003). Work conducted using an inclusive approach has demonstrated its value in enabling a consideration of shared experiences of disability. This is reflected within a review of the existing knowledge base (Morris and Wates, 2006), in a review of both services and parent and family experiences by the (then) social care regulator (Commission for Social Care Inspection [CSCI], 2009)¹ and through the work of the national UK organisation Disabled Parents Network (www.disabledparentsnetwork.org.uk, 19 February 2010).

The basis of this categorisation is the social model of disability which has been developed by the disabled people's movement in Britain. In this context, this means that many of difficulties faced by parents who have additional support requirements can be best understood by recognising disability as 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Barnes, 1991: 2). Where 'disability' is instead used to refer directly to parental impairment or chronic (mental or physical) health concerns, the door is kept locked against a fuller analysis of structural and cultural (*including* service based) barriers, which some disabled people (and their families) can find they have to navigate. Whilst there can also be particular issues faced by parents and their families as a result of the experience of specific impairments, the intention within this analysis is to maintain a focus on disability to examine policy.

Morris (2001) has considered the implications of a failure to engage with disability as social disadvantage and restriction of activity, and questions an analysis that instead equates disability (i.e. understood as impairment) with dependency, and further with a need for 'care'. She presents the consequences of understanding disabled women who are mothers through this lens. The resulting approach is one that focuses on 'care', specifically leading to a concentration on 'young carers':

Children of disabled parents have been described as "little angels" who are forced to "neglect their school work and friends" in order to look after us. However, if we apply the social model of disability to the situation of disabled mothers we can see that there are a number of social factors which create the situation in which children might have to provide some help to their parents. (Morris, 2001: 7)

The dangers identified are that poverty, single parenting, discriminatory professional attitudes, inappropriate services and disabling environments (including housing) become marginal in policy and practice understandings and responses. Further, as noted above, disability is one of the significant forces that can shape family life where a parent has an impairment or long-term health difficulty. Jones *et al.* (2002) conducted research with black families (involving participants from a range of minority ethnic communities), which included young people providing support to family members, primarily parents. Their work demonstrates the importance of a focus on the causes of social inequality

rather than its consequences. The authors conclude that categorising 'children and young people as "young carers" ignored the complexity of caring roles within family life, and risked masking or perpetuating the social inequality experienced by the whole family' (Jones *et al.*, 2002: 40). The study further highlights the strengths that existed within families, particularly in relation to parenting which supported children's development, where parents were managing in difficult circumstances and often with unmet social care needs. The fear that services might view a child of a disabled parent as 'in need' or 'at risk' was a barrier to seeking support and could result in anxiety for parents, even where individual workers were experienced positively.

Fear of a child-in-need response as a barrier has been identified and examined previously (Wates, 1997; Morris, 2003; Olsen and Clarke, 2003; Morris and Wates, 2006) as well as in more recent work (CSCI, 2009). If services are to be accessible and responsive, and perceived as such by families experiencing the more severe consequences of social inequality, then developing a family-focused approach from a 'risk-based' starting point has an inherent problem: the risk of 'building in' a barrier to support. The learning gained from examining disabled parent's experiences of services can usefully inform an appraisal of the *Think Family* approach, which has an explicit focus on risk.

Support for disabled parents and their families

There has been more than a decade of awareness within policy debates concerning the obstacles parents and their families can face in having their needs appropriately met. During this time, there have been significant developments, in services for adults, that have demonstrated the potential to improve support that recognises disabled parents' parenting role. These include the implementation of direct payments (made by a local authority so that an individual can purchase their own support directly) and the development of both individual (cross-service) and personal (social care) budgets, where resources available to individuals are made explicit to enable the organisation of personalised support (Glasby and Littlechild, 2009). These methods of developing tailored support are dependent on the success of local implementation, appropriate assessment and individuals meeting eligibility criteria for support, and may not be considered a solution by all individuals and their families (CSCI, 2009).

The body of research work which has identified that disabled parents can experience difficulties when trying to access appropriate services that support the parenting role (including Wates, 1997; Goodinge, 2000; Olsen and Clarke, 2003; Olsen and Tyers, 2004; Tarleton *et al.*, 2006; Kilkey, 2007; CSCI, 2009) demonstrates that two principal difficulties continue to persist: the extent to which a 'gap' exists between children and families' and adults' services; and the extent to which the parenting role is recognised and responded to within adult social care.

The Department of Health's Social Services Inspectorate (Goodinge, 2000) identified that a lack of flexibility between services presented an obstacle to delivering support to disabled parents and their families. The report recommended that strategic approaches should be developed between social care services (and other agencies) to ensure a more holistic approach to support. This report provided an impetus for local councils to develop protocols to provide a joined-up approach, reflected in Wates' (2002) survey of 125 councils in England. She found that just under half of responders either had intentions to develop their work in this area (29 councils) or had developed (often early stage)

protocols (31 councils). Subsequent work within four council areas, where there was active engagement in developing a strategic approach with disabled parents, examined policy, practice and experience (Olsen and Tyers, 2004). This identified the recognition of disabled parents' mothering or fathering *role* ('Think Parent') as fundamental to delivering joined-up, needs-led support:

Disabled parents are individuals, with possible needs for assistance as individuals. However, they also have responsibility for children, and for their development and quality of life, and work with them must be aware of their needs as parents and of the potential (positive and negative) impact [of] any work with them on their ability to parent successfully. (Olsen and Tyers, 2004: 79)

It is this recognition of both the potential *positive* and *negative* impact of services on parent and family experience, identified in relation to disabled parents' experiences of services during the past decade (Olsen and Wates, 2003; Olsen and Clarke, 2003; CSCI, 2009), that is often missing from discussion of the 'risks' families face. Both Goodinge (2000) and the more recent regulator study by the CSCI (2009) have shown that local councils most often do *not* identify disabled parents as a specific group of people who may use local services (with implications for both local strategic planning and commissioning). The visibility of disabled people with parenting responsibilities is obscured by a tendency to limit interest in disabled people's personal and family relationships *unless* either 'carer' support or risk concerns are identified, as considered by Morris (2001) earlier. A narrow understanding of disability is fundamental here:

We were concerned to find that although, according to senior managers, the social model of disability guided the council's work this did not follow through into their staff's actions. The focus of staff appeared to be either on the children in the family or on the impact of the adults' disability on their personal needs. Workers rarely looked beyond this and seldom focused on the whole family and how to support and help the parents in the discharge of their parental duties in their social setting. (Goodinge, 2000: 2)

And nine years later:

[A] social model of disability set out in policies and protocols may not necessarily be translated into practice, especially when staff do not fully understand the model or where these policies may not relate to every service in a local area. Assessment processes often did not appear to reflect the social model of disability and adult services assessments often focused on the degree or nature of a parent's impairment, linked to local eligibility criteria. (CSCI, 2009: 32–3)

A resource guide to support the development of local policies and protocols has been developed by Morris and Wates (2007). This built on their knowledge review of research, policy and practice (Morris and Wates, 2006) conducted for the Social Care Institute for Excellence, which included a review of two approaches that have been undertaken within councils: those which focus on specific parent 'needs' such as mental health, physical impairment, or learning disability; and a 'universal' approach based on an inclusive definition of disabled parents. Their analysis provides a clear steer for the

development of local strategies that can mitigate against the fragmentation of services through an inclusive approach:

A key advantage of a universal protocol, when used in addition to specific procedures covering particular groups of parents, is that it establishes the principle that support should be made available to all parents in a way that families experience as nonstigmatising and approachable. The division of services into relatively impermeable compartments can be a source of great frustration and difficulty for families whose needs span administrative categories. A universal protocol means that possibilities for continuity and flexibility are maximised, and provides a framework within which specialised services can be accessed as and when needed. (Morris and Wates, 2007: 14)

Although there has long been recognition of the difficulties faced by disabled parents and their families, where gaps between services are not strategically bridged there continues to be fragmentation in many localities. The CSCI (2009) study surveyed 50 councils in England about their knowledge, approach and policy concerning disabled parents and their families. The study reports that councils identified a range of barriers to the development of more flexible services, which suggests that national policy could do more to support local developments.

A specific barrier for some councils was that energies had been diverted into the integration of children's services (social care and education). It was widely recognised that management across directorates would need to work together to prioritise supporting disabled parents, particularly where practice staff across children and families' and adults' services had less contact and information sharing due to reorganisation. Two thirds of the 50 councils reported that their local policies tended to focus separately on adults' and children's services, and only just over 10 per cent reported that a 'whole family focus' featured within local strategy. Fifteen councils had developed joint working protocols for supporting disabled parents, 12 of which were universal in their approach, and these had often led to demonstrable improvements for disabled parents and their families. This was dependent on front-line staff having knowledge of the implications for their direct work and on successful engagement of all partners (including specialist services, for example in relation to mental health or substance misuse).

The capacity of adults' services to deliver appropriate support to disabled people who have parenting responsibilities is fundamental to the success or otherwise of any joint arrangements across services. *Fair Access to Care Services* (FACS) Guidance (Department of Health, 2002) has provided an Eligibility Framework for adult social care, graded into four bands ('Critical', 'Substantial', 'Moderate' and 'Low'), which describe a range of different risks to independence and well being if community care needs are not addressed. This framework is used at council level to derive local eligibility criteria, with different authorities providing access at different levels. When applying eligibility criteria to assessments of social care support needs, there is a requirement to consider whether individual support requirements would increase without services being organised, which could move the individual into a higher (eligible) band.

Crucially, this framework has included family and social roles and responsibilities within the criteria. This means that there is a 'critical' risk to independence and well being if a vital family or social role and associated responsibilities (e.g. parenting) cannot be undertaken, and a 'substantial' risk if the majority of (non-vital) family/social roles cannot be performed. The Department of Health (2003) clarified within practice guidance that there is no hierarchy of support requirements, so that a risk to maintaining social roles is

of the same importance as other risks (such as to being able to carry out personal care tasks unassisted).

A review of the guidance on eligibility criteria for adult social care has recently been undertaken, and a consultation process has been conducted. The review followed an examination of the implementation of current criteria within social care by CSCI (2008). This study surveyed opinion amongst different stakeholders, including people who use or seek to access services, local and national organisations representing those using services and managers and those delivering services within social care. The report highlighted concerns that a tension existed between the FACS approach (concerned with standardising the application of eligibility criteria) and the more recent drive towards personalisation in social care (focused on processes including self-assessment and choice and control in the organisation of social care support). Following this work the Department of Health (2010) has issued new guidance on adult social care eligibility criteria in the context of personalisation; as well as stressing that social care services need to sit alongside accessible universal services, this retains the four existing bands and recognition that support requirements in relation to family roles are of equal importance to other risks to independence and well-being.

The CSCI (2009) study of services for disabled parents and their families identified some potential in the local implementation of the personalisation agenda; however, most councils who took part were at an early stage of developing their approach to individual and personal budgets. Some parents and their families, involved in the study through workshop activity alongside service representatives and practitioners in four council areas, were unsure about whether these approaches would work for them. Concerns were voiced about the local availability of appropriate care at different times of the day and uncertainty was expressed concerning whether cash-for-care approaches could be pooled in ways that would support the family as a whole. There was also evidence of tailored approaches to care, including use of both individual budgets and direct payments: whilst some parents are benefiting, these were largely considered a *potential* groundbreaker in changing disabled parents' experiences of services within the community.

The way in which support is delivered, and who has access to control it, is only one part of the story: insufficient funding for adult social care was explicitly referred to within the CSCI (2009) study, as many disabled parents under existing eligibility criteria within their locality could not qualify for publicly funded support. It is unclear whether this in part reflects the way in which the criteria are applied, and whether support requirements that relate to the parenting role were felt to be sufficiently considered (or indeed easy to express) within assessment processes. Concerns were voiced in some localities that assessments could be service-led and impairment focused, in part driven by (resource managing) eligibility criteria. The adequacy of funding for the development of personalised adult social care has elsewhere been termed 'the critical question' (Lymbery, 2010: 19). This is crucial given government commitment to the management of the limited resources allocated, alongside proposals to provide free (non-means-tested) personal care to those who have the most substantial support needs (Department of Health, 2009) and the commitment to maximising choice and independence. In addition to the specific difficulties identified in adult social care, and in the relationships between adult social care and children and families' services, there is a wider challenge; that is, to ensure that parents are represented meaningfully within debates concerning social care service organisation and delivery to *families*, including those families considered most at risk of marginalisation.

Family minded policy?

Alongside developments currently being progressed in adult social care, there have been policy developments at a national level focused on responding to family support requirements through integrating services and developing the provision of specific interventions. The founding of the Department for Children, Schools and Families in 2007 (now the Department for Education) had significance here, having signalled a commitment to an explicit *family* policy within the UK. It is important however that family policy is not only the remit of one department and that the implementation of policy across government and service structures is considered as an ongoing process. Commitment to this was indicated through the role of the Cabinet Office's Social Exclusion Task Force (SETF) in developing the *Think Family* approach to support for families, particularly those facing multiple forms of exclusion (SETF, 2008; DCSF, 2009a). *Think Family* is relevant to disabled parents and their families if they seek to use services for three reasons: some families which include a disabled parent experience multiple causes of disadvantage; a focus on 'families at risk' has the potential to prioritise the use of a risk lens when assessing the support requirements of family members, and may obscure an understanding of disabled parents' experiences of services and of parenting; and there are messages within *Think Family* with implications for social care services for families not considered to be at high-level risk of social exclusion.

To inform *Think Family*, the SETF conducted a review of *Families at Risk* (SETF, 2007) drawing on available evidence about the experience of specific disadvantages. The SETF review was predicated on an understanding that there exists a residual problem of a small number of families experiencing or at risk of exclusion, in contrast to a majority who experience increased wellbeing. Of primary concern were the 2 per cent of families, identified through analysis of the 2005 Families and Children Study, who experience five or more of a 'basket of disadvantages'. These disadvantages (where language use reflects the operationalisation of disability relevant concepts within the survey) were presented as follows: no parent in the family is in work; family lives in poor quality or overcrowded housing; no parent has any qualifications; mother has mental health problems; at least one parent has one long-standing limiting illness, disability or infirmity; family has low income (below 60 per cent of the median); or the family cannot afford a number of food and clothing items. The analysis conducted is then used to support an approach locating many family difficulties as arising from a parental problem. Risk within a family was associated explicitly with a parent's own need for support, their ability to mitigate against risks faced by their children and their ability to be present as a source of resilience for them. The account put forward does enable individual and family difficulties to be considered within a life-span context, however it pins both parental 'difficulties' and their (asserted) consequent resource implications at the centre:

When parents experience difficulties in their own lives, the impact can be severe and enduring for both themselves and for their children. The consequence can cast a shadow that spans whole lifetimes and may carry costs for public services and the wider community. (SETF, 2007: 4)

There was an additional focus on a number of risks implied to be inherent in parental experience of long-standing health difficulties or impairment. For instance, a direct line was drawn between presence of mental ill-health and increased risk of

'childhood psychiatric disorder' (SETF, 2007: 20). Here both 'genetic' and 'environmental' transmission paths were identified uncritically: this is problematic given the lack of consideration given to social inequality and disability. It is, however, unsurprising as intergenerational transmission of disadvantage, where parental risk factors are considered a core conduit, has been a policy concern preceding the *Families at Risk* review. Indeed, it has been articulated within both Labour and Conservative administrations (Parton, 2009). Similarly, detrimental impacts of parental poor health or 'disability' were identified, with consequences for young people being specifically distilled into the risk of becoming a 'young carer'. This, then, illustrates the line of analysis by Morris (2001) presented above and demonstrates how consideration of disability and 'care' without reference to social barriers results in a conceptualisation of dependent-carer relations in families that include a disabled person (Parker and Clarke, 2002).

Despite the individualising inherent within a parent as risk focus, the SETF (2007) analysis recognised that individualising family difficulties overlooks resources within a family and asserted that support should build on 'family strengths'. Individuals in their own right (with specific strengths) are not strongly represented within this account, and parental strengths are reformulated as 'resilience'. Parents providing resilience are those who demonstrate appropriate control and warmth with their children, who support their development of social and emotional skills and who support their educational development (SETF, 2007: 12–13). The presence of these features in parent-child relationships protects those families with parental problems from developing severe disadvantages. Thus parental strengths are considered in narrow child developmental terms, and technical accounts of risk are being narrated within policy documents which do not directly include an account of the impact of either disabling barriers or of services on individuals' and families' lives.

There are, however, more system-wide and practice-focused elements within the *Think Family* approach, with key characteristics defined as follows: adults' and children's services should have no 'wrong door' (to ensure the right support is delivered, and that this is not dependant on which professional has the initial contact); services should look at the whole family; services should build on family strengths; and services should provide support tailored to need (SETF, 2008). Although the *initial* focus of the *Families at Risk* review was one that focused on a minority of parents, here we can see acknowledgement that the implications of this focus go beyond a small minority of families. This is reinforced when system change is articulated as fundamental to ensuring a family-focused approach can be delivered. Within the findings of the *Families at Risk* review the SETF (2007: 57) stated that 'We need a system that **thinks family** from Whitehall to the frontline.' When presenting this approach in greater depth (SETF, 2008), the importance of thinking family *across* Whitehall was also acknowledged, clearly mirroring the recognised challenge faced within some councils to work across administrative boundaries.

It is useful to specifically consider current debates about adult and children and family services in historical context. Parton (2009) has reviewed policy focused on children and families' social work and highlights the irony of the call to *Think Family* emerging just as 'social services' were widely recast into separate adults and children and families directorates. He contrasts recent developments with those initiated within the 1968 Seebohm Report, which led to the formation of social services departments, argued to be preferable to organisationally separate adults' and children's services, with greater potential to achieve a holistic (including a family) approach:

Think Family had many similarities to the Seebohm Report but with two important differences: adults were not conceptualised in their own right but only as their behaviour might impact on children; and it did not place social workers at the centre of the development. (Parton, 2009: 76)

The *Think Family* approach could be considered explicitly in relation to *both* adult and children and families social work (and other professions and roles), yet this is not reflected within current (child-welfare-focused) policy: multi-professional working at the practice level is, however, implied as important if 'thinking family' across the 'frontline' is to be achieved.

The re-alignment of children's and adults' social care services so that they can meaningfully cooperate in meeting both individual and family needs remains a central challenge to family-focused policy (James, 2009) and was recognised as such within the *Think Family* documents. This has been responded to through the funding of 15 *Family Pathfinders* within English councils. These Pathfinders have been set up to 'develop new ways of delivering intensive support to families at risk and to ensure that adults' and children's services work more effectively together' with a specific aim to 'develop learning on how systems change across adults' and children's services can improve support for vulnerable families' (DCSF, 2009b: 1). Six 'Extended' Pathfinders received additional funding to develop systems of support for families which include 'young carers', recognising that many young people do not receive support until they have taken on an inappropriate level of responsibility within their families (DCSF, 2009c). The support requirements of disabled parents who actively manage, often within challenging circumstances, to protect their children from significant caring responsibilities are not explicitly considered. This focus on risk to young people as 'carers' results in disabled people within families being represented as people who are 'cared for' rather than having active roles, such as parenting.

Within the guidance provided to support the development of a *Think Family* approach there is some evidence that adults' services have been defined in an inclusive way. Adults' social services are not, however, strongly asserted within guidance for practitioners who are informed simply that 'there are many different social services available from LAs [local authorities]. These include services provided to adults suffering from physical or mental disabilities' (DCSF 2009d: 6). This reflects how 'disability' has been used across *Think Family* documents to mean impairment, indicating that the structural, cultural and interpersonal ways in which disability is sustained has not been integrated into the analysis.

Conclusions

The development of the *Think Family* approach, and its implementation at a local level, was based on recognition that there are a minority of families whose significant support requirements have not been addressed and that ways of working with families should therefore be embedded across adults' and children and families' services. This mirrors the concerns of those disabled parents who have faced difficulties in accessing appropriate support which recognises their family role and responsibilities. There is significant learning which has been developed in research and through strategic developments in local councils to address the barriers faced by disabled parents. This has not been reflected

in the analysis, strategy and guidance developed within the *Think Family* stream of work and therefore signifies that 'think parent' is required in order to adequately 'think family'.

The inherent dangers which exist within family-focused social policy that is predicated on a risk-focused analysis requires interrogation. Any focus on 'risk' in families which include a disabled parent has consequences for the approachability and appropriateness of services and could make aspirations to ensure that there is 'no wrong door' difficult to achieve. Risk-focused analysis has explicitly supported an understanding of disability largely limited to the problematisation of impairment and a focus on 'care'. Developing an integrated approach to supporting families, from Whitehall to the frontline, should be conducted with acknowledgement of its relevance to individuals and families beyond those most marginalised and be based on an analysis which addresses the complex social causes of inequality.

Note

1 The Commission for Social Care Inspection (2009) worked with Harriet Clarke, Nathan Hughes and Rosemary Littlechild to undertake their *Supporting Disabled Parents* study and to prepare the report.

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